

ANNUAL STATUS REPORT



The Kentucky Commission on Services and Supports for
Individuals with Intellectual and Other
Developmental Disabilities

Submitted in Accordance with KRS 210.577 to:

Governor Matt Bevin
and the General Assembly
October 2018

KENTUCKY COMMISSION ON SERVICES AND SUPPORTS FOR INDIVIDUALS WITH INTELLECTUAL AND OTHER DEVELOPMENTAL DISABILITIES

Fiscal Year 2018

INTRODUCTION

In accordance with KRS 210.577(3), the Kentucky Commission on Services and Supports for Individuals with Intellectual and Other Developmental Disabilities respectfully submits the following report for the period of July 1, 2017 through June 30, 2018. The Kentucky Commission on Services and Supports for Individuals with Intellectual and Other Developmental Disabilities was created and established by KRS 210.575 through the enactment of House Bill 144 by the 2000 General Assembly. This commission hereafter referred to as the HB 144 Commission or the commission, serves in an advisory capacity to the Governor and the General Assembly concerning the service system that affects the lives of people with intellectual and other developmental disabilities (I/DD).

MEMBERSHIP

The commission's membership in 2018 included 24 individuals representing an array of stakeholders. Nine of these positions are appointed by the Governor to serve four-year terms and include representation of family members, provider organizations, advocacy groups, and self-advocates. Four members of the General Assembly are appointed and the remaining 11 members are stipulated in KRS 210.575 and include representation from the Secretary of the Cabinet for Health and Family Services (CHFS), departments within CHFS, the University Center of Excellence in Disabilities at the University of Kentucky, and the Commonwealth Council on Developmental Disabilities.

During the 2017 reporting period, recruitment for a self-advocate was conducted and eligible applicants were submitted to the Office of Boards and Commissions for review and appointment. On August 8, 2017, Ms. Lesley Reising was appointed to the commission to fulfill Jim Chesser's term representing self-advocates.

During the 2018 reporting period, the commission conducted recruitment activities for two positions. Gayle DiCesare retired from her position at RiverValley Behavioral Health, a community mental health center, and was no longer eligible to serve as representative of a direct support provider. On March 7, 2018, Mr. Steve Shannon was appointed to fulfill Ms. DiCesare's term. In September 2017, Mr. Michael Smith, self-advocate, resigned his position. A packet containing information of eligible applicants has been forwarded to the Office of Boards and Commissions for review and appointment of a self-advocate. As of June 30, 2018, a self-advocate has not been appointed to serve the remainder of Mr. Smith's term.

The list of commission members and their term expirations as of June 30, 2018, are included in Appendix A of this report.

COMMITTEE INFORMATION

During FY 2012, the commission formed three committees to address issues and concerns identified from data collected through the National Core Indicator (NCI) project, in which Kentucky has participated since 1998. The committees are: (1) Health and Wellness, (2) Participant Directed Supports, and (3) Community Integration. The NCI survey provides a variety of data reported by adults with intellectual and developmental disabilities and their family members about the quality of services and supports received through a variety of funding sources. A NCI Quality Improvement committee was established in 2010 to analyze the data and provide the commission with information that resulted in the identification of four priority areas: (1) health and wellness; (2) employment; (3) psychotropic medication usage; and (4) relationships and community inclusion. Each year the NCI Quality Improvement committee reviews findings and provides updates and recommendations to the commission. The priority areas have remained consistent. The priority areas and updated data were shared with the committees in FY 2018.

The three committees met throughout the reporting period and each committee identified issues of concern to its members. Members of the committees included commission members who serve in leadership capacities as chair and co-chairs of the committee; self-advocates; family members of individuals with disabilities; and representatives from the Department for Behavioral Health, Developmental and Intellectual Disabilities (DBHDID), the Department for Aging and Independent Living (DAIL), the Department for Medicaid Services (DMS), Protection and Advocacy (P&A), the Department for Public Health (DPH), and the Transportation Cabinet. Following is a brief synopsis of the identified goals and objectives of each committee for FY 2018.

Health and Wellness

The Health and Wellness Committee met on two occasions during FY 2018. Efforts continued in the collaboration with multiple partners to develop a survey about health/wellness issues. The Committee, in collaboration with the Division of Developmental and Intellectual Disabilities (DDID), attempted to gather data from the Health Risk Screening Tool (HRST) related to the use of psychotropic medications. Barriers were identified related to data collection and accuracy so the committee asked for provider input. The committee received regular updates from the Human Development Institute (HDI) regarding health/wellness initiatives and provided input on continued efforts. Four formal recommendations were submitted in June 2018 to DBHDID for consideration and written response.

Participant Directed Services (PDS)

The PDS committee met on three occasions during FY 2018. The PDS committee seeks to promote the principles and tools of self-determination that are used in the PDS program to assist participants in the creation of meaningful, culturally appropriate lives within their community in

order to develop relationships, learn, work and earn income, and actively participate in community life. The committee discussions focused on the following topics: a direct support professional (DSP) registry that would not require state funding for development and sustainability; increased awareness of technology that encourages independent living of participants and a decreased need for direct support services; accessible training made available to Medicaid waiver recipients and families; and a review of the Participant Directed Services manual currently available through the Arc of Kentucky. The committee received updates from DMS related to the Home and Community Based Waiver redesign efforts. The committee submitted one formal recommendation for consideration by the Cabinet during FY 2018.

Community Integration

The Community Integration committee held five meetings during FY 2018 and primarily focused efforts on transportation services. Through meetings with representatives from the Transportation Cabinet and DMS, the committee was able to discuss areas of concern related to availability of accessible transportation services for people with intellectual and other developmental disabilities. The conversations resulted in the distribution of a letter of clarification to DMS certified transportation and home and community based waiver services providers to ensure all providers received the same information and guidance. This was a short-term solution while the committee continued discussions of long-term solutions for the provision of accessible, affordable, transportation services that enable people with disabilities to seek employment, further develop community relationships, and complete activities of daily living. The committee did not submit formal recommendations during FY 2018.

STRATEGIC PLANNING

Prior to the June 2018 quarterly meeting, the commission held a special session for the purpose of identifying strategic goal areas to drive the commission's efforts in the upcoming five fiscal years (FY 2019 – FY 2023). Dr. Vestena (Tena) Robbins, Policy Analyst within DBHDID facilitated the special planning session.

Recommended goals and committee structural changes will be presented to the commission for consideration at the next quarterly meeting, scheduled for September 14, 2018.

FY 2018 GOALS, INITIATIVES, and ACTIVITY UPDATES

In 2012, HB 144 Commission members, in collaboration with DBHDID, established five long-term goals as part of a 5-10 year plan. The commission reviewed the goals in FY 2018 and agreed these goals are still applicable to its work. The following goals, updates, and committee reports reflect commission activities in FY 2018.

Goal 1: Community education and outreach must combine efforts to create an awareness of need and available services for people with intellectual and other developmental disabilities (IDD).

Initiative 1

The PDS Committee proposed the following recommendation in March 2018. The commission accepted and submitted the recommendation to the Cabinet for Health and Family Services.

Recommendation: The HB 144 Commission recommends the Department for Aging and Independent Living (DAIL), Department for Medicaid Services (DMS), and the Division of Developmental and Intellectual Disabilities (DDID) collaborate with members of the HB 144 Participant Directed Services Committee and other identified self-advocates, family members, and advocacy organizations to update the Participant Directed Services Participant Manual. The revised edition should contain applicable information for both the Supports for Community Living (SCL) and the Michelle P. Medicaid waiver programs, along with information that participants and family members may use for the recruitment and retention of direct support professionals to provide participant-directed supports.

Response: DAIL acknowledged the recommendation and provided the following response:

As the contracted entity of DMS for all home and community-based services waiver PDS administration, DAIL vetted this request through the Division of Community Alternatives within DMS. It was determined that the manual(s) would be reviewed and modified during waiver redesign. Presently the available manual(s) and guidebook(s) are specific to the supports for community living (SCL) and home and community based (HCB) waivers; however, the overall concept of PDS, self-direction, rights and responsibilities, timesheets, etc., can be applied to any waiver with PDS, and may therefore be used as a resource. DAIL recognizes that some components of the PDS manual are inaccurate due to a recent regulation change incorporating the MWMA and Caregiver Misconduct Registry; however, no other significant changes have occurred that would create irrelevance to the manual. Therefore, the referenced manual will be revised in the process of waiver redesign.

Initiative 2

The PDS committee discussed the current lack of availability of training regarding participant-directed services from DAIL targeted for providers of services. The committee discussed the training needs of both self-advocates and their families that could be addressed through avenues such as videos, accessible on YouTube, or other social media sites, as a way to address ongoing community outreach and education.

Goal 2: Promote inclusion of citizens with disabilities to increase natural supports in the community and in the workplace.

The HB 144 Commission did not provide recommendations related to goal 2 to CHFS during FY 2018.

Goal 3: Advocate for adequate funding for a system of services and supports throughout the individual's lifespan.

The HB 144 Commission did not provide recommendations related to goal 3 to CHFS during FY 2018 although advocacy is ongoing.

Goal 4: People with disabilities and their families will have continued access to services and supports that meet their needs and expectations.

Initiative 1

Vast health disparities exist for Kentuckians with disabilities. Kentuckians with disabilities are more likely to have high blood pressure, be obese, smoke, and be inactive than those without disabilities in the commonwealth and the nation¹. The Health and Wellness committee continued its efforts to positively influence the overall health and well-being of individuals through involvement in the following activities:

Activity: In partnership, the Kentucky Department of Public Health, the Kentucky Division of Developmental and Intellectual Disabilities and the Human Development Institute continued year two efforts of the Community Health Education and Exercise Resources (CHEER) project to improve health outcomes for people with intellectual disabilities and mobility impairments. This is a five-year Centers for Disease Control and Prevention (CDC), Disability Branch funded program that launched in July, 2016.

Activity: Three Health and Wellness committee members served on the Project CHEER advisory committee. The CHEER advisory committee evaluated and provided feedback on developed resources and website (<http://www.wellness4ky.org>) content and provided guidance to the Project CHEER leadership related to project goals and deliverables.

Activity: Health and Wellness committee members began development of a provider survey around health and wellness issues.

Activity: The committee, in collaboration with the Division of Developmental and Intellectual Disabilities (DDID), continued to gather data from the Health Risk Screening Tool (HRST)--related to the use of psychotropic medications--and identify barriers related to data collection and provider input concerning this issue for those receiving SCL residential services. National Core Indicators (NCI) data found the percentage of people in Kentucky enrolled in the SCL waiver reported to take at least one medication for mood disorder, anxiety, and/or psychotic disorder was 56% while the NCI national average was 50%.

Four formal recommendations were accepted by the commission on June 8, 2018 and submitted to DBHDID for consideration and written response.

Recommendation 1: The National Core Indicator Quality Improvement Committee had recommended review of HRST data as part of its 2017 report. However, initial review indicated that further analysis, of the high proportion of people taking psychotropic

¹Centers for Disease Control. (2015). *Disability impacts all of us: A snapshot of disability in Kentucky*. Author

medications, data is needed to gain a better understanding of this issue. The Health and Wellness Committee recommends review of Medicaid medication claims data with the assistance of the Department for Medicaid Services.

Response: The recommendation was filed in June 2018. A formal response from DDID will be presented to the commission in September 2018.

Recommendation 2: DDID and representatives from HRST develop and provide training to provider agencies on the importance of medication accuracy and entering end dates when entering HRST data.

Response: The recommendation was filed in June 2018. A formal response from DDID will be presented to the commission in September 2018.

Recommendation 3: The development of a process to accurately enter medications, and review and update the medication list each time a SCL Medicaid waiver recipient goes to the doctor. This shall include updating HRST data for those receiving residential services.

Response: The recommendation was filed in June 2018. A formal response from DDID will be presented to the commission in September 2018.

Recommendation 4: DDID shall complete an audit of records for anyone whose current record shows that the individual is taking six or more psychotropic medications, and shall make appropriate referrals based upon those audits.

Response: The recommendation was filed in June 2018. A formal response from DDID will be presented to the commission in September 2018.

Initiative 2

The Community Integration committee met throughout FY 2018 and focused efforts on the following activities:

Activity: The committee reviewed the needs and issues surrounding transportation for individuals with intellectual and other developmental disabilities. Representatives from the Department for Medicaid Services and the Transportation Cabinet who administer the Non-Emergency Medicaid Transportation program were invited to become members of the committee and provide input and guidance in exploring short-term solutions for identified problems. An area of great concern was the multiple interpretations of the regulation regarding the scheduling and availability of transportation provided by certified transportation brokers. A short-term resolution was reached by consensus. Thus, a clarification notice was issued by the Transportation Cabinet and DMS, to all transportation brokers, and shared with providers of the supports for community living and Michelle P. Medicaid waiver programs. The committee continues to study alternative solutions regarding accessible and affordable transportation for people with intellectual and other developmental

disabilities, to access their communities, for purposes of employment and community engagement.

Activity: In addition to transportation, the Community Integration committee continues to explore how people with disabilities, including those who may have specialized health care needs, may utilize tools and strategies such as community mapping, supported decision-making, and peer support to increase community engagement.

Initiative 3

The Participant Directed Services (PDS) committee continued to explore the development and sustainability of a direct support professional (DSP) registry for purposes of recruiting, employing, and retaining qualified staff for needed services. The committee continued to research how organizations such as the Kentucky Association of Private Providers (KAPP), the Kentucky Association of Regional Providers (KARP), and other non-governmental agencies may collaborate to develop, maintain, and sustain a registry system available to participants and/or provider agencies, for the purpose of recruiting qualified direct support staff.

Initiative 4

A member of the HB 144 Commission, Dr. Kathy Sheppard-Jones, also served on the Work Matters Taskforce's Disability subcommittee. The efforts of the taskforce resulted in the signing of an executive order by Governor Matt Bevin, declaring Kentucky as an Employment First state and creating the Employment First Council to serve as an advisory body of state government. The executive order declares that it is the "policy of the Commonwealth of Kentucky that competitive and integrated employment in the community shall be considered the first and primary option for persons with disabilities of working age who have communicated a desire to become employed."

Initiative 5

Four agencies with representation on the HB 144 Commission are among the collaborating partners on KentuckyWorks, a systems-change effort focused on increasing the percentage of students with the most significant disabilities transitioning from school to work in the community by 20% over the life of the grant. The partners have come to understand that they must act as agents of change to affect all people with disabilities, families, employers, and professionals. This collaborative effort includes the University of Kentucky's Human Development Institute, the Kentucky Office of Vocational Rehabilitation, the Kentucky Department of Education, the Kentucky Division of Developmental and Intellectual Disabilities, Kentucky Protection and Advocacy, Kentucky Office for the Blind, the Commonwealth Council on Developmental Disabilities, the Kentucky Office of Autism, and the Kentucky Autism Training Center. Resources and additional information are available at their website: <http://www.kentuckyworks.org/>.

Goal 5: The primary focus for public intermediate care facilities (ICFs) will shift to expand networks providing a continuum of health care within the individual's community.

The HB 144 Commission did not provide recommendations related to goal 5 to CHFS during FY 2018 although advocacy is ongoing.

STATISTICAL INFORMATION

Following is the status of programs providing supports to individuals with intellectual and other developmental disabilities (I/DD) through FY 2018.

Community Mental Health Center (CMHC) Service Provision 2018

- Based upon data reported by the CMHCs, 9,575 people with I/DD were supported by the 14 CMHCs in FY 2018.
- CMHC adult I/DD crisis services were utilized by 1,254 individuals during the calendar year 2017.

ICF Average Census FY 2009 through FY 2018

The number of people who reside in state intermediate care facilities for individuals with intellectual disabilities (ICFs/IID) has decreased significantly following a 2006 settlement agreement between the Department of Justice and the Commonwealth of Kentucky in regards to the operation of the Oakwood ICF/IID. Pursuant to this settlement, a statewide transition process was implemented at all ICFs/IID, to successfully transition individuals into the community.

Facility	FY09	FY10	FY11	FY12	FY13	FY14	FY15	FY16	FY17	FY18
Oakwood	205	173	133	120	121	119	114	111	106	105
Hazelwood*	162	161	158	146	135	123	116	105	104	96
Bingham Gardens	34	32	28	24	23	21	21	24	24	21
Outwood	63	59	50	46	42	40	38	36	35	34
Total	464	425	369	336	321	303	289	276	269	256

*Hazelwood Center census includes the three 8-bed ICF community homes.

As part of the settlement agreement with the US Department of Justice, each of the state-owned ICFs/IID, continues transformation into a Center of Excellence. There are three medical specialty clinics in Kentucky. One located on the campus of Oakwood, one on the campus of Hazelwood, and one on the campus of Bingham Gardens. These centers serve as a resource to individuals, families, and community providers by offering specialized supports and services that otherwise are not accessible in the community.

Waiver Slots Funded FY 2015 through FY 2020

New Slots Funded

Waiver	FY15	FY16	FY17	FY18	FY19	FY20
Supports for Community Living (SCL) new slots	200	240	0	0	0	0
Michelle P (MP) new slots	250	250	0	0	0	0
Acquired Brain Injury (ABI) new slots	90	93	0	0	0	0
Acquired Brain Injury Long Term Care (ABI-LTC) new slots	60	60	0	0	0	118
Home and Community Based (HCB) new slots	0	0	0	0	0	0

Total Waiver Slots

Waiver	FY15	FY16	FY17	FY18	FY19	FY20
Supports for Community Living (SCL) total slots	4,701	4,701*	4,941	4,941	4,941	4,941
Michelle P (MP) total slots	10,250	10,500	10,500	10,500	10,500	10,500
Acquired Brain Injury (ABI) total slots	200**	383	383	383	383	383
Acquired Brain Injury Long Term Care (ABI-LTC) total slots	200**	320	320	320	320	438
Home and Community Based (HCB)	17,050	17,050	17,050	17,050	17,050	17,050

*240 slots were appropriated by the legislature for FY16; however, CMS approval of the SCL waiver renewal did not occur until March, 2018, therefore they were not available until then.

**Although additional slots were appropriated by the legislature for FY15, the slots were added to the waiver during FY16

CLOSING THOUGHTS

It has been a privilege for the Kentucky Commission on Services and Supports for Individuals with Intellectual and Other Developmental Disabilities to serve in an advisory capacity to the Governor and the General Assembly regarding the needs of persons with intellectual and other developmental disabilities. Commission members extend their gratitude to Governor Bevin for his support of the Employment First Initiative and signing of the executive order declaring Kentucky as an Employment First state. We also extend our appreciation to the members of the General Assembly for their continued support of quality services across the lifespan, for individuals with intellectual and other developmental disabilities. Along with the Department for Behavior Health, Developmental, and Intellectual Disabilities, the commission looks forward to meeting their goals to improve the quality of supports for the citizens of Kentucky.

The Cabinet for Health and Family Services and the Department for Behavioral Health, Developmental and Intellectual Disabilities extends their appreciation to the members of the commission for their advocacy on behalf of Kentucky's citizens with intellectual and other developmental disabilities. Their continued advocacy has positively produced change in such efforts as the Work Matters Task Force, community inclusion, and improving the health and wellness of people with disabilities across the lifespan.

APPENDIX A – Kentucky Commission on Services and Supports for Individuals with Intellectual and Other Developmental Disabilities

Cabinet for Health and Family Services Secretary	Tim Feeley, Deputy Secretary (Designee for Adam Meier, Secretary) 275 East Main St. Frankfort, KY 40621 (502) 564-7042 Tim.Feeley@ky.gov	Direct Service Provider- Representative of Kentucky Association of Regional Providers TERM EXPIRES 7/15/2019	Steve Shannon, Executive Director KARP, Inc. 152 W. Zandale Drive, Suite 201 Lexington, KY 40508 (859) 272-6700 (o) or (859) 509-5411 (c) sshannon.karp@gmail.com
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Office of Vocational Rehabilitation Executive Director	Becky Cabe 275 East Main St. 2-EK Frankfort, KY 40621 (502) 782-3437 Becky.Cabe@ky.gov	Family Member TERM EXPIRES 7/15/2020	Berlinda A. Bazzell 409 Doddy Church Road Scottsville, KY 42164 (270) 622-7819 pbazzell@nctc.com
University Center for Excellence in Developmental Disabilities - Human Development Institute Director	Kathy Sheppard-Jones, PhD, CRC 126 Mineral Industries Bldg. University of KY Lexington, KY 40506-0051 (859) 257-3045 kathleen.sheppard-jones@uky.edu	Family Member TERM EXPIRES 7/15/2020	Rita D. Wooton 2025 Bullcreek Road Hyden, KY 41749 (606) 672-6279 Rita_Wooton@yahoo.com
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Representative	Larry Brown Capitol Annex, Room Frankfort KY 40601 Larry.brown@lrc.ky.gov	Self-Advocate TERM EXPIRES 7/15/2019	Lesley Anna Reising 208 Dinsmore Street Berea, KY 40403 (859) 302-2722 Lesleyreising@yahoo.com
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